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(G) Caregiving

Issue Papers

Carolina B

Caregiving: Addressing the Needs of Family Caregivers

By

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CAREGIVING

Issue: Addressing the Needs of Family Caregivers

How do we, as a society, provide care for those aging citizens who are no longer able to function independently, now and in the future? Caregiving, which is one of the most personal of issues, has now become a major public concern. As the population ages, more Americans face the challenges of providing care to loved ones who need help. According to a recent National Long Term Care survey, over 7 million people are informal caregivers (spouses, adult children, other relatives and friends) to 4.2 million older persons with disabilities living in the community. Here in South Carolina there are over 390,000 family caregivers providing 419 million hours of care per year. (Arno, 2003)

Informal caregivers, family and friends, are the backbone of our long term care system. Family caregivers provide over 80% of all home care services. In fact, only about one-third of disabled elders use any formal (paid) home care. If the work of these informal caregivers had to be replaced by paid home care the cost would be \$45 to \$94 billion per year.

Most caregivers (63%) are helping the care recipient with four or more activities of daily living (bathing, dressing, toileting, transferring, eating) as well as instrumental activities of daily living (transportation, cooking and housework). (Johnson, 2001)

Research has found that 73% of caregivers provided care to a loved one for over 12 months. (Johnson, 2001) Family caregivers routinely underestimate the length of time they will be needed. Only 46% expected to be caregiving longer than two years, but the average length of time spent on caregiving is about eight years. (MetLife, 1999)

More than half of caregivers are balancing caregiving responsibilities and employment. The multiple responsibilities of the family caregiver produce a physical, psychological, emotional, social and financial "caregiver burden" which research indicates affects 50% of caregivers. Research has linked caregiver burden with caregiver illness and early placement of the care recipient into institutional long term care placement. (Johnson, 2001)

Suzanne Geffen Mintz, a family caregiver and president of the National Family Caregivers Association, has said, "As we become family caregivers, we add work to our already busy lives. Even though most of us very willingly and lovingly take on this added

responsibility, we must remember that we are doing just that, adding more responsibility and more work."

The National Family Caregiver Support Program was established in 2000 with the enactment of the Older Americans Act Amendments. The program was developed by the Administration on Aging and was modeled after already successful programs in several states and after listening to family caregivers themselves. The program calls for all states, working with area agencies on aging and local community service providers to have five basic services for family caregivers, including:

- Information to caregivers about available services;
- Assistance to caregivers in gaining access to services;
- Individual counseling, organization of support groups, and caregiver training to caregivers to assist the caregivers in making decisions and solving problems relating to their caregiving roles;
- Respite care to enable caregivers to be temporarily relieved from their caregiving responsibilities; and
- Supplemental services, on a limited basis, to complement the care provided by caregivers.

How are we, as a society, going to provide care for those who need assistance and support for those who care for them during the next ten years, twenty years and into the future?

Barriers

Informal caregivers often go unnoticed except by those depending on them for care. Society as a whole--policymakers, clergy, media, and employers—does not recognize the importance of the family caregiver.

Adequate supportive services are often not available. A survey of caregivers found that caregivers have varying needs for support services. The mostly cited needs were counseling for the care recipient, in-home health care, and home delivered meals. This survey also records that finances frequently prevent care recipients from getting the services they need. Many services are not covered by insurance. The other barriers cited by these caregivers were the "hassle factor" (not having services available at time of need, not being able to get off work, etc.) and the lack of knowledge of how to get services. (Johnson, 2001)

The need for respite care was reported by 39% of caregivers but only 19% received it. Respite care is not usually covered by Medicare, Medicaid or private insurance.

Research shows that caregivers with the highest incomes used more respite than others, perhaps indicating that cost of respite is a significant barrier. (Johnson, 2001)

The financial costs of caregiving create a barrier for caregivers. Caregiving families tend to have lower incomes than non-caregiving families. (NCFA, 2000) Research indicates that the out of pocket medical expenses for a family that has a disabled member who needs assistance with activities of daily living is more than 2.5% greater than a family without a disabled member. (Cunningham, 1999) One study found that 61% of the estimated 2.5 million Americans who need assistive technology can't afford it. (lezzoni, 2002) The cost of purchasing supportive services is another burden that often falls upon the family caregiver. Thirty eight percent of caregivers reported that they felt overwhelmed by the financial hardships caused by caregiving. (Johnson, 2001)

Solutions:

Informal caregivers need a wide range of support services to remain healthy, improve their caregiving skills and remain in their caregiving role. Caregiver support services must include information, assistance, counseling, respite, home modifications or assistive devices, support groups and family counseling. These support services can and do make a real difference in the day-to-day lives of caregivers.

Family caregivers can be empowered through a combination of information and education, problem solving, skill building, and support. These supportive services help families manage the complexities of their caregiving situations, increase competence and confidence in their caregiving role, and enhance their well-being.

Caregivers should have access to geriatric care coordinators who can bridge the gaps in services, assist in coordinating and supervising services, to support and enhance the caregiver's ability to continue to meet their care recipient's needs in the community.

Advocates for the elderly and disabled agree that, with proper patient-support services such as meal delivery and transportation to medical appointments, community-based care is a better option than nursing homes.

Recommendations:

Expansion of the Family Caregiver Support Program is needed to provide active, positive encouragement and support to family caregivers. The Family Caregiver Support Program in South Carolina provides trained advocates available to assist

caregivers seeking help. Expansion of the program would allow for the addition of advocates as well as more financial support to family caregivers.

We must provide the funding necessary to ensure that medical and supportive services to their health and care are provided to the elderly. Adequate funding for home and community based services to meet the health needs of the elderly is vital. But we must also ensure that these services are consumer directed, quality oriented and monitored to provide the framework needed to ensure that our seniors age with grace and dignity.

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Respite and Support Groups

By

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April 26th panel, Respite -11am session

Linda Cello, Program Manager for the Alzheimer's Association Palmetto Chapter

Issue: The numbers of caregivers are ever increasing as a result of the "sandwich generation" and the elderly spouses who now find themselves caring for their loved ones. Caregivers are in great need of "down time" and help as they provide the main source of patient care. Many do not know what respite is all about. Where is the help for these individuals? What is respite and does respite really exist?

Today's caregivers are rarely included in the continuum of care of the patient. Many are not acknowledged for what the do; often times not even by other family members who cannot or will not see the amount of work, frustration, anger, or selflessness that is required. Few recognize the stress that is placed on them. Caregivers are often lonely, isolated, and in need of someone to give to them. They are often loving, sometimes patient, gentle, tired, giving and many have had to become caregivers, although they never pictured themselves in this role.

Barriers:

Caregivers are a tough bunch. They are often guilt-ridden and they almost always declare that "No one can provide the quality of care that I can. I promised my mom that I would always take care of her." They are reluctant to ask for help. When they do, they often turn to family to help with the responsibilities and costs. Not all family members are willing to step up to the plate resulting in additional stress on the caregiver who thought they could count on family. There is often a lack of education about the illness or disease or respite itself. The good news is that respite does exist! The barrier is finding it, which may mean becoming creative. Respite is that break or downtime for the caregivers who desperately need time for themselves. Whether it is time to go out and grocery shop, walk on the beach or read a newspaper – it is a must so the caregiver can get a break and maintain a sense of self.

Many caregivers do not know that help may be available to them, and that there are several types of respite. They are often averse to talking about their own problems, always focusing on the patient. While their efforts are to be applauded, they must also realize that they cannot sacrifice their own health and relationships for total care-giving. It is important that they realize that they must care for themselves first to ensure that they will be healthy enough to provide care to the patient. It is now becoming clear that caregivers are placing themselves at risk for dying before the one they have been caring for.

As families spread out across the country, it may not always be feasible to count on loved ones to provide help in the care-giving process. Some may or may not be willing or able to send money to help. It becomes evident that caregivers must educate

themselves, families, and friends about the illness or disease and how much stress it is placing on the individual.

<u> April 26th - Panel – Respite Linda Cello</u>

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Solutions:

Where does this elusive respite come from? Respite can mean 15 minutes for reading, stretching, a cup of tea, or walking. It can mean allowing a willing neighbor to stay for 2 hours so you can get out of the house and get a taste of "normal, everyday activities." Neighbors and friends may be overlooked as potential relief, but sometimes friends may not call as often as they once did. When was the last time someone asked you, "How are you doing? Can I help?" How often do you turn them down? The "I can do it all syndrome" is a reality.

Caregivers need to be aggressive in researching all avenues of respite. One of the problems is that many are unaware of where to look or who to call. Many do not avail themselves to hospice care. Respite funding sources may be available to provide financial assistance, but where are they?

It is important to know what resources are available in your area. Councils on Aging are great places to start. Research the illness or disease and call national associations for information on local chapters that may provide help. Contact your church. Many have respite programs or volunteers willing to help. Surf the web if you have access to it or ask someone to do it for you. Visit the local Senior Center. Ask your doctor.

Accept help from others. Hospice is for the living and may provide free help if you meet the criteria. Support groups provide a great outlet where caregivers can discuss their situations with others who are going through similar problems. They are great places for problem solving and to get sympathetic ears to listen to you and for caregivers to learn from each other.

Recommendations:

Education and involvement! Reach out and contact federal, state and local representatives and tell them how much caregivers need financial support to provide respite. Contact the Silver Haired legislature and the AARP to voice your concerns, increase awareness, and gather support. You can make a difference!

Know what opportunities are out there. The Older Americans Act Amendment of 2000 provided a new program called The National Family Caregiver Support Program. This program was implemented to address the needs of caregivers by offering assistance to gain access to supplemental resources and information, as well as respite care. Contact agencies like the VA, state Family Caregiver Support Programs, and national associations.

The caregivers must educate themselves, their families, friends, and legislature. They must discuss their needs and stress levels. It is important to be proactive in seeking sources of increased respite funding.

Workplace Issues: Employees and their Elderly Parents

By

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ISSUE PAPER-SC WHITE HOUSE ON AGING APRIL 25-27, 2005 MYRTLE BEACH, SC

MARY PETERS, MS, CMC, RG PANELIST

STATEMENT OF THE ISSUE

Managing the care of aging parents or a disabled family member while trying to meet work and family responsibilities is a challenge that faces a rapidly growing segment of our work population. The Share The Care program, developed by Care For Life, Inc. is a workplace benefit for managing care for employees with elderly dependents.

As a result of increasing elder care responsibilities in the U.S. workplace, the U.S. Department of Labor Women's Bureau found that 29% of working caregivers had to rearrange work schedules, 21% reduced work hours, 19% to time off without pay, and 9% of the employee had to quit work to become a full time caregiver. The Bureau of National Affairs reported employer costs and problems related to eldercare, which include absenteeism, tardiness, visible signs of stress, excessive phone calls, requests for reduced hours, turnover, health problems, decreased quality of work and increased work accidents.

The impact of eldercare on employees and employers falls into five categories:

- 1. Replacement costs for employees who leave due to their caregiving responsibilities.
- 2. Increased use of sick leave and FMLA to care for an aging parent.
- 3. Costs due to work interruptions while the employee contacts doctors, home health aides and other paid workers.
- 4. Expenses and time spent supervising employed caregivers.
- 5. Lower productivity due to high rate of stress related disorders among working caregivers.

BARRIERS TO OVERCOME IN ORDER TO ACT ON THE ISSUE

Demographic Background Of Workers Gender Household Employment Form Of Care Living Arrangements

SOLUTIONS

Assessment Of Existing Dependent Care Benefits
Leave Of Absence Options
Flexible Spending Account Options
Geriatric Care Management Employee Assistance Programs
Long-term Care Insurance

RECOMMENDATIONS FOR ACTION

Needs Assessment Survey

All Employees Participate In The Process Of Program Development
Plan To Have Assistance Available For Fmployees With Needs In The Near Future
Allocate Resources For Communication and Training
Develop Organizational Philosophy For Programs To Manage Work and Family
Integration

Community Forums Report

(G) Caregiving

2005 WHITE HOUSE CONFERENCE ON AGING

COMMUNITY FORUMS

CAREGIVING

LOCATION OF EVENT: Florence Civic Center - Florence, SC

Priority Issues:

- A) Need to support caregivers
- B) Incentives to encourage family members to care for aging relatives
- C) Caregiver support: training, respite, information, referral, needs assessment and financial support for family caregivers
- D) Training and financial support for paid caregivers
- E) Grandparents raising grandchildren.

Proposed Solution(s):

- A) Recommend providing more flexibility in the delivery of services and reimbursing non-traditional service providers (e.g., friends, relatives, and neighbors). Seniors and their family members should not be limited to the type of service provider with whom they may contract for services.
- B) Recommend developing more varied home and community based services, including information and transportation, to enable seniors to maintain their independence and dignity.
- C) To serve more clients and to offer more services to these individuals, additional FCSP funds are desperately needed. We recommend a significant increase in funding for the FCSP.
- D) Recommend supervision from Social Service agencies to ensure persons are not being abused or neglected in the home environment.
- E) Increase public awareness of the Family Caregiver Support Program.
- F) Increase public awareness of Family Caregiver Support Groups.

LOCATION OF EVENT: Gaillard Municipal Auditorium – Charleston, SC

Priority Issue:

Unpaid caregivers are faced with financial challenges, a decline in their spiritual, emotional, and physical health, and lack the necessary training and support to keep care recipients in the home.

Barriers:

- 1) Inability to work outside of the home and provide full time care.
- 2) Lack of resources to pay for respite care, personal care, personal care items, and Medication.
- 3) Injuries in the home.

Proposed Solution(s):

- 1) Provide increased training to caregivers on financial management, proper techniques, and stress reduction.
- 2) Encourage private companies to provide on-site adult day programs.
- 3) Provide more community-based funded respite.
- 4) Encourage companies to provide family leave for caregivers
- 5) Use lottery dollars to fund programs for older adults.
- 6) Provide a monthly stipend to caregivers.
- Tax incentives for private companies donating funds to assist with caregiver services.

Recommendation:

To create more funding sources for senior caregiver services including more community-based programs for in-home care, caregiver training, respite, supplies, medication, and volunteer respite workers. Actively pursue and implement public, private and faith based partnerships, including tax credits and incentives for corporate participants and family caregivers.

LOCATION OF EVENT: Capital Senior Center – Columbia, SC

Priority Issue:

Lack of coordinated information and referral point; lack of case management; lack of services; lack of health insurance for working caregivers; lack of reward for thrifty seniors; hospital discharge planning is inadequate; long range impact on current caregivers that has future repercussions.

Barriers:

- 1) Cost;
- 2) Employer attitudes;
- 3) Status and pay scale of service providers;
- 4) Convenience of service to family;
- 5) Lack of truly knowledgeable information and referral staff;
- 6) Support groups should meet at convenient time and provide respite at the same location:
- 7) Lack of health information for family caregivers who would work part-time.

Proposed Solution(s):

- 1) Increase services for family caregivers in the areas of home modification, medication assistance, in-home supports such as personal care aides and respite providers.
- 2) Help working family caregivers by giving incentives to employers for family friendly policies and by changing health insurance policies so part-time workers can access it.

3) Strengthen information and referral function of AAA, improve education of caregivers; add case management for family caregivers or provide tax credits.

LOCATION OF EVENT: H. Odell Weeks Activity Center – Aiken, SC

Priority Issue:

Unpaid family caregivers are faced with financial challenges and t heir own life is "put on hold."

Barriers:

- 1) Lack of resources to pay for respite care, personal care, etc.
- 2) Inability to work outside of the home and continue to provide full time care for a loved one.
- 3) Lack of trained workers for in-home services such as respite care, personal care, etc.
- 4) Lack of Adult Day Care services.

Proposed Solution(s):

- 1) Provide increased training and support for caregivers.
- 2) Encourage agencies and/or private companies to provide adult day services.
- 3) Provide more community based funded respite programs.
- 4) Provide tax incentives for caregivers.
- 5) Provide training for unemployed persons to work in the health care field.

Recommendation:

To create more funding sources for senior services including more home/community based programs for in-home care.

LOCATION OF EVENT: Orangeburg County Council on Aging-Orangeburg, SC

Priority Issue:

Unpaid family caregivers are faced with financial challenges and their own life is "put on hold."

Barriers:

- 1) Lack of resources to pay for respite care, personal care, etc.
- 2) Inability to work outside of the home and continue to provide full time care for a loved one.
- 3) Lack of trained workers for in-home services such as respite care, personal care, etc.
- 4) Lack of adult day care services.

Proposed Solution(s):

- 1) Proposed increased training and support for caregivers.
- 2) Encourage agencies and/or private companies to provide adult day care services.
- 3) Provide more community based funded respite programs.

4) Provide tax incentives for caregivers.

Recommendation:

To create more funding sources for senior services including more home/community based programs for in-home care.

LOCATION OF EVENT: City Council Chambers – Rock Hill, SC

Priority Issue:

Caregiving is very important and must be widely supported.

Barriers:

- 1) Increased need for respite care but there is not adequate funding.
- 2) Increasing number of grandparents caring for grandchildren. Seniors need help caring for grandchildren.

Proposed Solution(s):

- 1. Establishing geriatrics best practices. This is being considered by the Southern Baptist Association.
- 2. Movement by the faith community to help.
- 3. Better care for residents is provided when they are able to remain in their home.
- 4. Volunteer programs would be helpful in increasing the awareness of seniors and their needs.
- 5. Telephone reassurance programs were beneficial before they lost their funding for staying in touch with seniors.

LOCATION OF EVENT: Santee-Lynches Regional Council of Governments – Sumter, SC

Priority Issue:

Age criteria.

Barriers:

Caregiving Program guidelines state program eligibility age is 60 and above.

Proposed Solution(s):

Restructure Older Americans Act to include people age 50 and above.

LOCATION OF EVENT: Emmanuel Baptist Church – Manning, SC

Priority Issue #1:

Financial assistance to family and non-family caregivers.

Barriers:

- 1) Federal government policies program funding restrictions; program restrictions.
- 2) Not enough money being utilized properly; mediators are not available to assess client needs (financially, etc.).

Proposed Solution(s):

- 1) Review government policies to ensure they are fair and adequate.
- 2) Increase funding and/or use appropriately.
- 3) More accountability with program and finances.
- 4) Base services provided on individual need, not group need.

Priority Issue #2:

Availability of a 24-hour caregiver.

Barriers:

- 1) Lack of funding.
- 2) Insufficient number of caregivers available to provide adequate coverage.
- 3) Lack of training.
- 4) Family members having insufficient time to devote to recipient.
- 5) Labor laws.

Proposed Solution(s):

- 1) More funding through other programs.
- 2) Improve communications to ensure families are aware of availability of caregivers.
- 3) Provide training to family and non-family caregivers.
- 4) Save money and to increase care, hire caregivers in nursing homes to relieve nurses.

LOCATION OF EVENT: Kershaw County Health Resource Center – Camden, SC

Priority Issue #1:

Funding for caregiving services.

Barriers:

- 1) Program has a lack of funding priority.
- 2) No tax breaks for caregivers.

Proposed Solution:

- 1) Obtain additional funding for program, to include private funding.
- 2) Rearrangement of priority funding.
- 3) Restructure tax code to provide tax breaks for caregivers.
- 4) Encourage long range family planning for future caregiver needs.

Priority Issue #2:

Training for caregivers.

Barriers:

- 1) All family members are not involved in the care of recipient (abandonment of family, needs to be a partnership).
- 2) Availability of caregiver to attend training due to lack of spare time too busy taking care of the recipient.
- 3) Lack of transportation to attend training.
- 4) No funding available to provide adequate training to caregivers.
- 5) No "train the trainer" courses available in the current caregiving program.
- 6) Lack of specialized caregiver training, especially Alzheimer's training.

Proposed Solution(s):

- 1) Take training classes into the home.
- 2) Fund so adequate training can be provided.
- 3) Recruit more trainers.
- 4) Ensure adequate respite care is given to the caregivers so they can attend training and receive rest and relaxation.

Priority Issue #3:

Respite

Barriers:

- 1) Insufficient number of respite relief workers.
- 2) Inadequate funding available to fulfill respite needs.
- 3) Inadequate number of facilities that provide care while caregiver is in respite.
- 4) Care facilities/services too costly.
- 5) Caregivers have inadequate medical training.

Proposed Solution(s):

- 1) Medicare and Medicaid should be changed to allow funding for respite.
- 2) Train other family members to provide assistance to ensure primary caregiver has sufficient respite.
- 3) Seek out trained volunteer caregivers.
- 4) Establish affordable private care so primary caregiver can have sufficient respite.

<u>Focus Group Concern:</u> Lack of caregiving oversight due to care being provided in-home, occurrence of diverse situations, vastness of caregiver responsibilities, and privacy/autonomy requirements.

LOCATION OF EVENT: The Shepherd's Center – Sumter, SC

Priority Issue:

The education of caregivers.

Barriers:

1) Inability to access training sessions.

- 2) Insufficient marketing of existing programs and services.
- 3) Lack of trainers.

Proposed Solution(s):

- 1) Provide in-home training.
- 2) Establish a volunteer respite worker program to free up caregivers.
- 3) Increase the number of caregiver support groups.
- 4) Increase knowledge level of buddy call program.

LOCATION OF EVENT: Bethlehem United Methodist Church – Bishopville, SC

Priority Issue:

Care recipient income not sufficient to cover high costs of in-home care.

Barriers:

- 1) Medicaid's income eligibility requirement (to qualify for Medicaid) is too restrictive. Annual limit is currently \$4,000 and under.
- 2) Eligibility age to qualify for the Caregiver Program is too high (currently 60+).
- 3) Cost of healthcare service, healthcare providers, and caregivers too high.

Proposed Solution(s):

- 1) Provide training to seniors who wish to be caregivers at little or no $\cos t a$ "win, win" for both parties (would provide much needed work for seniors; these caregivers could provide more affordable assistance to recipients than what is currently available from existing agencies.
- 2) Increase level of personal income to receive Medicaid.
- 3) Make available affordable health care services, providers and caregivers, publish a list of available affordable caregivers that have received training.
- 4) Lower age qualification for family caregiving program assistance and health care assistance.
- 5) Increase funding.
- 6) Promote volunteerism.

Focus Group Concern: Lack of funding for caregiver relief.

LOCATION OF EVENT: Upper Savannah AAA – Greenwood, SC

Priority Issue:

Health care concerns, including sitter services to help with caregiving; services to help grandparents who are raising grandchildren.

Barriers:

- 1) Trust.
- 2) Personal finances.
- 3) Information overflow or not enough information.
- 4) Communication.

5) Lack of resources

Proposed Solution(s):

- 1) Provide information to local churches and doctors to dispense information on services.
- 2) Use community festivals to get information out about available services.